

INSIDE THIS ISSUE



Second Annual PDBP Meeting p.1



Patients' Corner: Walk It Together p.1



Anxiety and Catastrophic Worry in Parkinson's Disease p.2



What is a lumbar puncture? p.2



Participant Enrollment Update p.3



Spotlight on PDBP Projects p.4

Second Annual PDBP Meeting

On September 22, 2014, PDBP investigators, clinical coordinators and data management experts, representatives from non-government organizations, and NINDS Program staff met at the NIH Neuroscience Center in Bethesda, Maryland to discuss progress over the last year and set future goals.

The program enters its third year with patient enrollment at nearly 73% of total projected and several biomarkers being tested and validated. Collectively, over 44 papers have been published. The Program's award winning Data Management Resource has been updated to include new clinical resources available to researchers, powerful data mining tools and soon, information on common DNA variations associated with PD will be added. ■



The PDBP team in front of NIH Neuroscience Center



J-Lynn Conrady (right), who suffers from PD, is taking part in PDBP at the Penn State site. His wife, Harriet (left), is also participating as part of the control group.

Walk It Together

Patients' Corner

A retired administrative manager, used to efficiency and hard work, Conrady was determined to tackle his PD the best he could. "He always had a sense of hope," his wife of 54 years said. "We are going to deal with this together. Whatever it's going to mean, we're going to walk it together."

One of the first things Conrady did was enroll in the PDBP study at Penn State Milton S. Hershey Medical Center. "We've come such a long way in figuring out so many treatments, but still we're not happy with the end point yet," said Dr. Xuemei Huang of the Penn State PDBP site.

Dr. Xuemei Huang, a neurologist at Hershey conducting the research trials in which Conrady is taking part, said now is an exciting time for promising research.

Please see *Walk It Together* on page 3

Health Tips

Anxiety and Catastrophic Worry in Parkinson's Disease

By Gregory Pontone, M.D.

"Being aware of the timing of anxiety episodes in relation to the timing of your PD medications is the key to treating fluctuation-associated anxiety." – Dr. Gregory Pontone, Johns Hopkins University

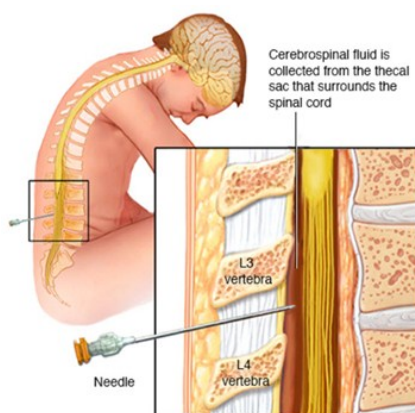
Severe anxiety and worry occurs in up to half of people diagnosed with Parkinson's disease (PD). Most often, the anxiety is new and out of character, with individuals reporting, "I never considered myself an anxious person before PD." In addition to causing emotional distress, anxiety has also been shown to worsen PD symptoms, lower quality of life, and cause people to avoid activities they once enjoyed.

Anxiety related to Parkinson's often has unique features and requires specialized treatment compared to anxiety not related to PD, including anxiety experienced before the onset of PD in the same individual. The two most common Parkinson's-related anxiety disorders are, 1) fluctuation-associated anxiety and 2) anticipatory anxiety.

Fluctuation-associated anxiety occurs as PD-medication wears off at the end of dose. Typically, this is an episodic anxiety with physical symptoms of racing heart, sweating, increased tremor, a feeling of restlessness, panting or trouble drawing a full breath, and even the fear that one might die. Being aware of the timing of anxiety episodes in relation to the timing of your PD medications is the key to treating fluctuation-associated anxiety. With this information, your doctors can adjust your medications to improve this type of anxiety.

Anticipatory anxiety is excessive worry about an upcoming event, such as an appointment or trip. Fear is out of proportion to the situation and there is the

Continued on page 4



© MAYO FOUNDATION FOR MEDICAL EDUCATION AND RESEARCH. ALL RIGHTS RESERVED.

What is a lumbar puncture?

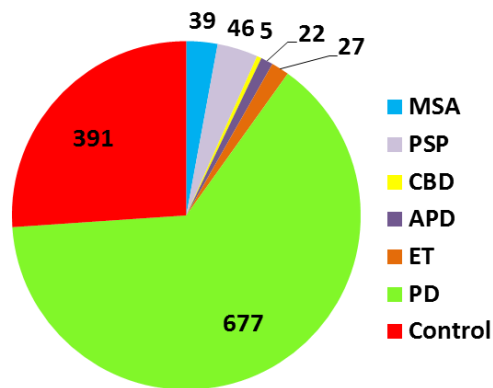
A lumbar puncture, or spinal tap, is an outpatient (in the office) procedure. It allows a small amount of cerebrospinal fluid, the fluid which bathes the brain and spinal cord, to be collected.

During the procedure, a small needle (a bit thicker than a human hair) is gently inserted into the back, after numbing medicine is injected into the skin and muscle tissue. Then the fluid is gently withdrawn. After that, the needle is withdrawn. It is a straightforward procedure with a low risk. Some people experience headache after the procedure. In order to reduce the risk of headache, a caffeinated beverage and increased fluid intake, as well as lying down as much as possible, is often recommended. Your doctor will have specific advice regarding what you should do after a lumbar puncture. The entire procedure takes about half an hour. ■

"It is a straightforward procedure with a low risk."

Participant Enrollment Update

As of January 22, 2015, a total of 1207 participants has been enrolled in the PDBP. This represents 82% of the total anticipated enrollment for the Program.



Number of PDBP participants based on diagnosis

Walk It Together from page 1

At Hershey, there are studies on what causes the disease, new ways to give dopamine-like drugs, and effective tools to measure which drugs work best.

The Conradys participate in a research study that is attempting to prove that MRI is an effective tool to gauge whether drugs are protecting brain cells from dying off due to Parkinson's disease. Harriet Conrady, like many spouses of patients with a vested interest in the research, also participates as part of the control group.

"If we can use MRI to provide the measurement of cell death that occurs in Parkinson's patients, we can know which drugs are truly neuroprotective. Right now, we know the drugs we use help with symptoms, but we don't have any proven way to know they actually stop progression of the disease in the brain," Huang said. Conrady feels fortunate to have been diagnosed early and that he didn't get the disease until he was in his 70s. The average age of onset is 62, but Huang has patients in their 30s.

"When people hear that they have Parkinson's disease, the first reaction is 'Why me?'" said Huang. "They feel like Parkinson's disease is a stigma for their life, but I tell them, 'Don't let Parkinson's define you.' I tell them to be physically active, stay mentally alert and stay socially connected.' Live the fullest life you can." Conrady heard her message loud and clear ■ **Adapted from Pennlive.com**

"We've come such a long way in figuring out so many treatments, but still we're not happy with the end point yet." Dr. Xuemei Huang

Spotlight on PDBP Projects**Developing imaging tools for assessing neurodegeneration in Parkinson's Disease****Increased free water in the substantia nigra of Parkinson's disease: a single-site and multi-site study**

One of the common features of PD is the selective loss of dopaminergic neurons in the area of the brain called the substantia nigra (SN). A number of brain imaging techniques e.g. MRI and PET, have been used to visualize these areas but there are ongoing efforts to improve this technology to allow for better assessment of the extent of neurodegeneration. Recently, Dr. David Vaillancourt and colleagues compared the “free water” index of MRI in the SN of PD patients and controls from a PDBP cohort and a multi-site PPMI cohort. The free water value was higher in the posterior region of the SN of PD participants than that of control subjects in both the single site and multi-site studies. This increase in free water appears to be related to deficits in dopamine transport and cognitive function. Future studies are needed to better understand the relationship between free-water values and various metrics of neurodegenerative processes. Nevertheless, these findings suggest that free water may be a useful index/metric to monitor in future therapeutic trials focused on modifying the SN in PD. [*Neurobiology of Aging* 2014, October 24.](#) ■

Anxiety and Catastrophic Worry from page 2

concern that the worst may happen. This type of anxiety is often due to a breakdown in the ability to organize, sequence, and plan. Treatment often involves the cooperation of family and caregivers and sometimes talk-therapy and medications.

Anxiety is not a sign of weakness or a lack of ‘mental toughness’; instead it is thought to be part of the disease process or a complication of anti-Parkinson’s treatment. There is no need to suffer in silence or embarrassment as these anxiety problems are common in Parkinson’s and can often be successfully identified and treated in a matter of weeks. ■

Dr. Gregory Pontone is an Assistant Professor in the Department of Psychiatry and Behavioral Sciences at Johns Hopkins University.

Editorial team:

Coryse St. Hillaire-Clarke (Editor-in-chief)
Karen David
Jenna Linde
Andrey Kuzmichev

Contact:

PDBP-OPS@mail.nih.gov

